
A Brief Guide to Pancreatic Cancer

Written by Dr.
Michele Molinari

Edited by Barb Fry

Second Edition

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Molinari M, Walsh M, DeCoutere S, Condon-Oldreive S.

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Stefanie Condon-Oldreive, is a school teacher and founder of Craig's Cause Pancreatic Cancer Society in Nova Scotia. Craig's Cause is named after Stefanie's father who developed pancreatic cancer and died from complications after undergoing a Whipple procedure. Stefanie has been very active in promoting awareness and fundraising to support research for pancreatic cancer. Craig's Cause aims to provide information about pancreatic cancer, to help patients and their caregivers by connecting them with other individuals affected by the same disease and by funding research on pancreatic cancer. Craig's Cause Pancreatic Society is in the process of reaching out to pancreatic cancer patients and their families in other Canadian Provinces by creating local chapters that will promote education and support for further research projects.

Michele Molinari, MD, is an assistant professor of surgery at QEII Health Science Centre in Halifax. He is board-certified in general surgery by the American College of Surgeons and member of the American Society of Transplant Surgeons. After graduating in general surgery at the University of Illinois at Chicago he completed his fellowship at the University of Toronto in hepato-biliary and pancreatic surgery. In addition he trained at the University of Alberta, Edmonton, in solid organ transplant surgery. Dr. Michele Molinari has specific interest in clinical outcome research and decision analysis for diseases of the liver, pancreas and biliary system.

Mark Walsh, MD, is an assistant professor of surgery at QEII Health Science Centre in Halifax. He is Canadian board-certified in general surgery and member of the American Society of Transplant Surgeons. Before graduating from the medical school at University of Toronto, Dr. Walsh completed a research fellowship at Harvard University in Boston studying lipid metabolism. He graduated in general surgery at Dalhousie University and then he completed his fellowship at the University of Toronto in hepato-biliary and pancreatic surgery and solid organ transplantation. Dr. Mark Walsh has specific interest in benign and malignant diseases of the liver, pancreas and biliary system.

Sarah De Coutere, RN, is a research coordinator for the Department of Medicine (Infectious Diseases) and Department of Surgery (Hepatobiliary and Pancreatic Diseases). Sarah is interested in clinical decision and clinical outcome research and patient's education for medical and surgical pathologies.

INTRODUCTION

This booklet and video is intended to provide educational materials for all those who are impacted by pancreatic cancer. In knowing that knowledge is power, it is our hope that these will provide patients, families, and caregivers with important tools that will help in the understanding, treatment, and management of this illness.

The Pancreas

The Pancreas is an important organ of the digestive system located deep in the upper part of the abdomen, behind the stomach and in front of the spine. The pancreas is called the "hidden organ" because it is located deep in the abdomen behind the stomach. About six to eight inches long in the adult, the organ contains thin tubes that come together like the veins of a leaf. These tubes join to form a single opening into the intestine that is located just beyond the stomach.

The pancreas produces juices and enzymes that flow through these tubes into the intestine, where they mix with food. The enzymes digest fat, protein, and carbohydrates so they can be absorbed by the intestine. Pancreatic juices, therefore, play an important role in maintaining good health. The pancreas also produces insulin, which is picked up by the blood flowing through the organ. Insulin is important in regulating the amount of sugar or glucose in the blood.

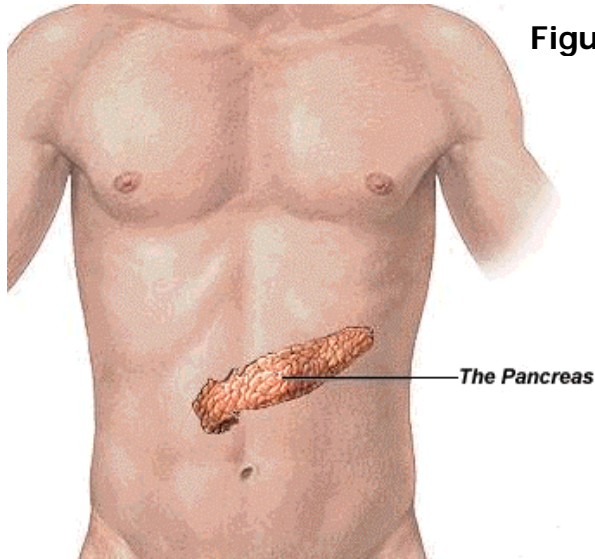
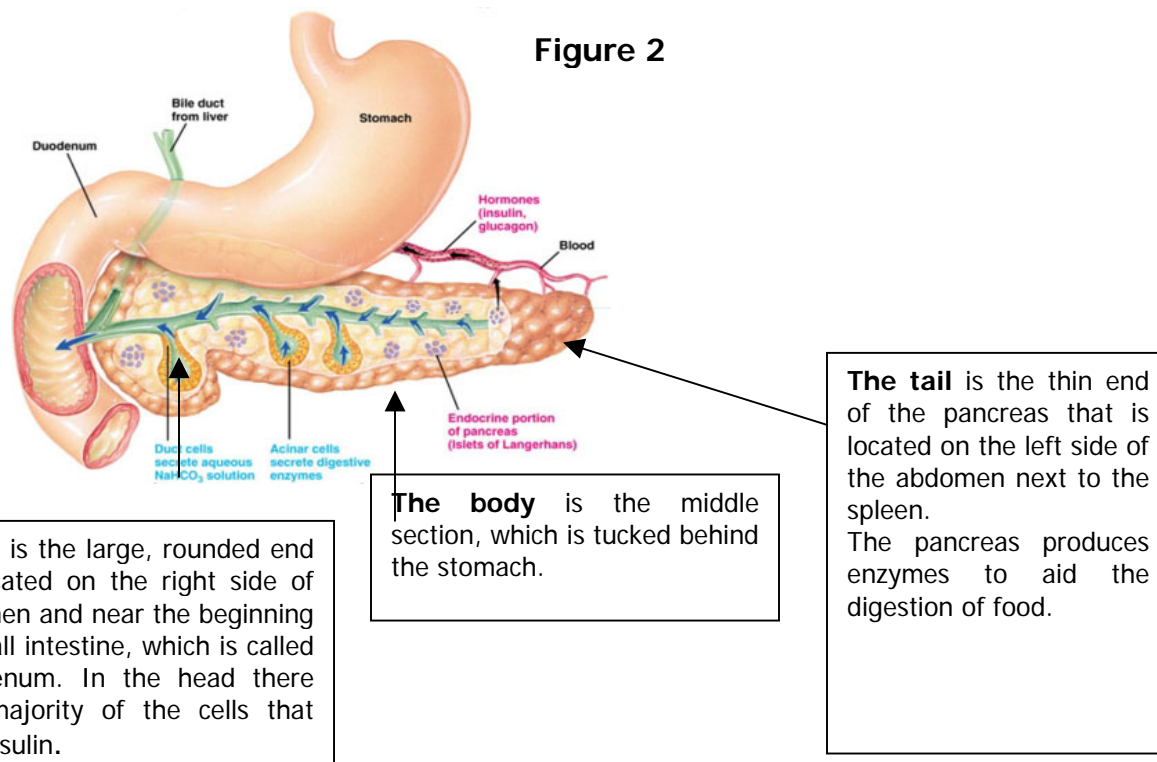


Figure 1

The pancreas has the function of producing insulin and other hormones and some of the digestive juices. As many other organs, the pancreas is divided in three regions: the head, the body and the tail. This helps doctors and nurses to identify correctly the areas of the pancreas that can be affected by problems.

The pancreas produces insulin that helps to control the level of blood sugar in the body during, after and between meals. Patients with poor insulin production become diabetic. In addition, the pancreas produces juices that are responsible for the digestion of food. There are other hormones that are produced by the pancreas such as glucagone or VIP that are important but not indispensable for life.



What Are the Diseases of the Pancreas?

A number of problems can occur in the pancreas. These include:

- Diabetes mellitus
- Acute pancreatitis
- Chronic pancreatitis
- Pancreatic enzyme deficiency
- Pancreas tumor

Diabetes Mellitus

Many cases of diabetes are caused by a deficiency of insulin. Insulin is needed to help glucose, which is a major source of energy, enter the body's cells. It is not known why insulin-producing cells in the pancreas die off. When they cease to function, glucose accumulates in the blood and eventually spills into the urine. These patients require daily insulin injections. More importantly, high blood glucose levels, over time, result in significant changes in blood vessels in the eyes, kidneys, heart, legs, and nerves. Damage to these vital organs represents the major risk for patients with diabetes.

Acute Pancreatitis

This condition occurs when the pancreas becomes quickly and severely inflamed. The major causes are:

- Heavy alcohol ingestion
- Gallstones or gallbladder disease
- Trauma
- Drugs
- High blood fats (triglycerides)
- Heredity
- Unknown factors

Binge alcohol drinking is a common cause of acute pancreatitis. Gallbladder disease, especially where a gallstone becomes lodged in the main bile duct next to the pancreas, also causes this condition. Accidents, such as the upper abdomen hitting the steering wheel during a car accident, can cause pancreatitis. Certain drugs, such as diuretics, can produce the disorder as can extremely high blood fat levels (triglycerides). Heredity seems to play a role since in some families the condition develops in several members of the family. Finally, there are the occasional cases that occur for unknown reasons. In pancreatitis, the digestive enzymes of the pancreas break out into the tissues of the organ rather than staying within the tubes (ducts). Severe damage to the pancreas then results.

Pancreas Enzyme Insufficiency

Digestive enzymes from the pancreas are necessary to break down protein, fat, and carbohydrates in foods that are ingested. When there is a deficiency of these enzymes, nutrients are not broken down, resulting in malnutrition and weight loss. This condition is called malabsorption because the intestine is unable to absorb these vital nutrients.

The two major symptoms are diarrhea (frequently with fat droplets in the stool) and weight loss. This condition can result from any cause of pancreatitis, including trauma and infection. Pancreatic enzymes can be taken by mouth to replace those no longer made by the pancreas.

Pancreatic Tumors

The pancreas, like most organs of the body, can develop tumors. Some of these are benign (not cancerous) and cause no problems. However, some benign tumors can secrete hormones which, when present in high levels, have a damaging effect. For example, insulin can be secreted in excessive amounts and result in dangerously low blood sugar levels (hypoglycemia). Another hormone called gastrin can stimulate the stomach to secrete its strong hydrochloric acid causing recurrent stomach and peptic ulcers, with many complications. Fortunately, there is much that can be done about these tumors.

Cancer of the pancreas is a serious malignancy (cancer) which is difficult to treat. Pancreatic cancer occurs in middle- or older-aged people, with the first symptom often

being dull pain in the upper abdomen that may radiate into the back. At times, skin jaundice (yellow skin color) occurs when the bile duct, which carries yellow bile from the liver and through the pancreas, is blocked. Surgery is the only effective form of treatment for pancreatic cancer.

OVERVIEW OF PANCREATIC CANCER

About one in 79 people will develop pancreatic cancer) over their lifetime. In North America in 2007, pancreatic cancer was responsible for the fourth highest number of deaths among cancer patients. The risk of developing pancreatic cancer is about the same for both men and women. Pancreatic cancer is sometimes called a silent disease because it is difficult to detect and symptoms do not usually appear until the cancer has grown for quite some time.

The Whipple procedure (pancreaticoduodenectomy) is the only treatment that can potentially cure pancreatic cancer. This operation consists of removing the head of the pancreas, part of the intestine and bile duct. Although the risk of death after this procedure has decreased significantly in the past decades, postoperative complications are still high. Because of these risks, pancreatic surgery is indicated only for certain patients. Despite improvements in the radiographic imaging of suspected pancreatic tumors, 5-10% of patients still have surgery where the presence of non-cancerous inflammation is found in the pancreas and parts of the organs that were removed.

UNDERSTANDING PANCREATIC CANCER: THE VIDEO

The video entitled '**Understanding Pancreatic Cancer**' that accompanies this booklet was created to better inform individuals who are suspected of having pancreatic cancer and their families. It is based on the idea that the more individuals and families know about the challenges they face in having pancreatic cancer the better able they are to make informed decisions about their treatment and management of this illness.

Over the last few decades, scientific knowledge on pancreatic cancer has made some progress. Nevertheless, there are still many aspects of this disease that are not completely understood yet.

This video discusses key issues and information that patients and their families should know about and consider. One of most important points is that even though pancreatic cancer may be suspected its existence must be proven. This can be done by removing a tumor sample with a small needle and examining it under the microscope. Until this is done a diagnosis of pancreatic cancer cannot be confirmed.

When faced with of a diagnosis of cancer, most patients and their families may feel fearful, overwhelmed, and unprepared to deal with all the information about their illness and new reality. During this time individuals and families may find it difficult to ask questions to their doctors and nurses. Because the treatment options of suspected

pancreatic tumours are complex, when patients are given recommendations on what can be done to improve their chances of cure or improved quality of life, they may have further difficulty processing this information and fully understanding the effects and impact of their treatments. Therefore it is vitally important for them to have a variety of educational materials that are factual, readily available, and clearly presented.

PANCREATIC CANCER

The word “cancer” is used to describe any one of a group of diseases in which the cells are abnormal, grow out of control, and can spread. Pancreatic cancer occurs when abnormal cells grow out of control in the tissue of the pancreas and form a tumour. A tumour is an abnormal growth of tissue in any part of the body.

Because the pancreas lies deep in the abdomen, a doctor performing an examination on a patient would not be able to feel a pancreatic tumour. Pancreatic cancer has no early warning signs, and there are no effective screening tests to make your doctor able to recognize this problem when still in the early phase. As a result, pancreatic cancer rarely is discovered near the beginning of its growth. Many times the diagnosis is not made until the cancer has spread to other areas of the body.

Spread and metastasis: A major concern when diagnosing a pancreatic cancer is whether or not the cancer has already metastasized (spread) outside the pancreas. The location of the metastases will determine whether the patient has local disease (contained in the pancreas and around the area of the tumor) or metastatic disease (the tumor has already spread to other organs). The location of the metastases will also determine whether the cancer is surgically removable or not. There are certain sites that pancreatic cancer may spread to that may make surgery not possible, They are:

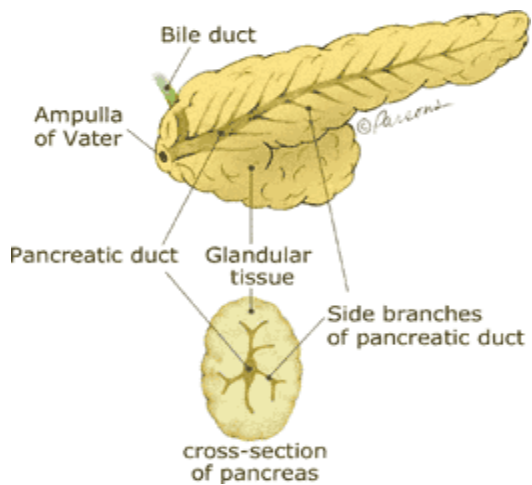
1) Lymph nodes: Metastases to lymph nodes do not automatically eliminate surgery as a possibility. The location of the affected lymph nodes makes a big difference. For example, the lymph nodes between the duodenum and the pancreas are a very common site of metastases. They are routinely removed during surgery. However, the spread of cancer to lymph nodes closer to the liver, may mean the tumor cannot be surgically removed. Typically, pancreatic cancer first metastasizes to regional lymph nodes, then to liver, and less commonly, to the lungs. In some cases, pancreatic cancer may invade surrounding internal organs (duodenum, stomach and colon).

2) Liver: Metastases to the liver are a common finding especially with tumors in the tail and the body of the pancreas. If there is evidence of liver cancer, surgery will usually not be an option.

3) Coeliac (Celiac) plexus: These are the nerves for the area of the pancreas and surrounding organs. These are the nerves that cause back pain when a growing tumor presses on them.

Haematogenous	50%
Lymphatic	50%
Local Infiltration	30%

Types of Pancreatic Cancer



The most common types of pancreatic cancer are originating from the lining of the pancreatic ducts. This type of cancer is called adenocarcinoma.

Adenocarcinoma of the pancreas can invade nearby tissues and organs. Cancerous cells can also spread through the blood and lymphatic system to other parts of the body. When this occurs, it is called metastatic cancer and it may be life-threatening.

Figure 3: Anatomy of the pancreatic ducts.

About two thirds of all pancreatic cancers form in the head of the pancreas. The other third form in the body and tail. These tumours are malignant, meaning they can invade nearby tissues and organs.

Tumours of the pancreas can also form in the cells which produce hormones such as insulin. These types of rare tumours are most often are benign. The malignant ones are called islet cell cancers or malignant pancreatic endocrine neoplasms. Other rare forms of pancreatic cancer are reported in table 2 and they will not be discussed further in this video as they are relatively rare.

Table 1 Rare forms of pancreatic cancer

Endocrine Tumors	Gastrinomas Glucagonomas Insulinomas Somatostatinomas VIPomas
Cystic Tumors	Mucinous cystic neoplasms Serous cystic neoplasms Solid pseudopapillary tumors Cystic Islet Cell Tumors Intraductal papillary Mucinous neoplasms (IPMNs)

Causes of Pancreatic Cancer

Genetics

All the cells in the body follow important instructions that regulate their lives and allow the well being of all living organisms. The instructions that control the lives of all cells come from their genes. When cells grow and divide, their genes sometimes make mistakes that result in the creation of defective cells. When abnormal cells become disorganized and continue to grow and divide, they form a mass that is also called cancer.

The abnormal cells that cause pancreatic cancer may be either inherited from a parent or most of the times they are acquired (just made on their own).

Inherited pancreatic cancer is passed on from one generation to another. Acquired pancreatic cancer develops during a person's lifetime, either as random abnormal cells or in response to injuries from harmful environmental factors such as exposure to radiation or chemicals.

Risk Factors

There is a long list of risk factors for pancreatic cancer. Some of the most important ones are reported in the following table.

Table 2: Known risk factors for pancreatic cancer

- **Advanced age:** Most of the pancreatic cancers occurs in people in their 60's, 70's and 80's.
- **Race:** Pancreatic cancer is more common in African Americans than in Caucasians
- **Smoking:** Smokers develop pancreatic cancer more than twice to three times as often as nonsmokers
- **Diet:** Pancreatic cancer may be associated with high intakes of meat and fat
- **Medical factors:** Pancreatic cancer is more common in patients who have a history of cirrhosis (a chronic liver disease), chronic pancreatitis, diabetes, and surgery to the upper digestive tract.
- **Environmental factors** : Long-term exposure to certain chemicals, such as gasoline and related compounds, as well as certain insecticides, may increase the risk of developing cancer of the pancreas.
- **Genetic predisposition:** As many as 10% of all cases of pancreatic cancer are related to genetic disorders (e.g., BRCA2 gene mutation, PRSS1 gene mutation, hereditary non-polyposis colorectal cancer [HNPCC; Lynch syndrome], Peutz-Jeghers syndrome).

Risk factors you cannot influence: your age and family history.

Risk factors you can influence include:

Smoking: People who smoke have two – three times the chance of getting pancreatic cancer compared with people who do not smoke.

Diet: A diet high in cholesterol, fried foods, and processed meats, such as bacon and sausage, may increase the risk of pancreatic cancer, while a diet high in fruits and vegetables may reduce the risk of pancreatic cancer.

Obesity: People who are overweight are 20 times more likely to develop pancreatic cancer compared to those who are not overweight.

SIGNS AND SYMPTOMS OF PANCREATIC CANCER

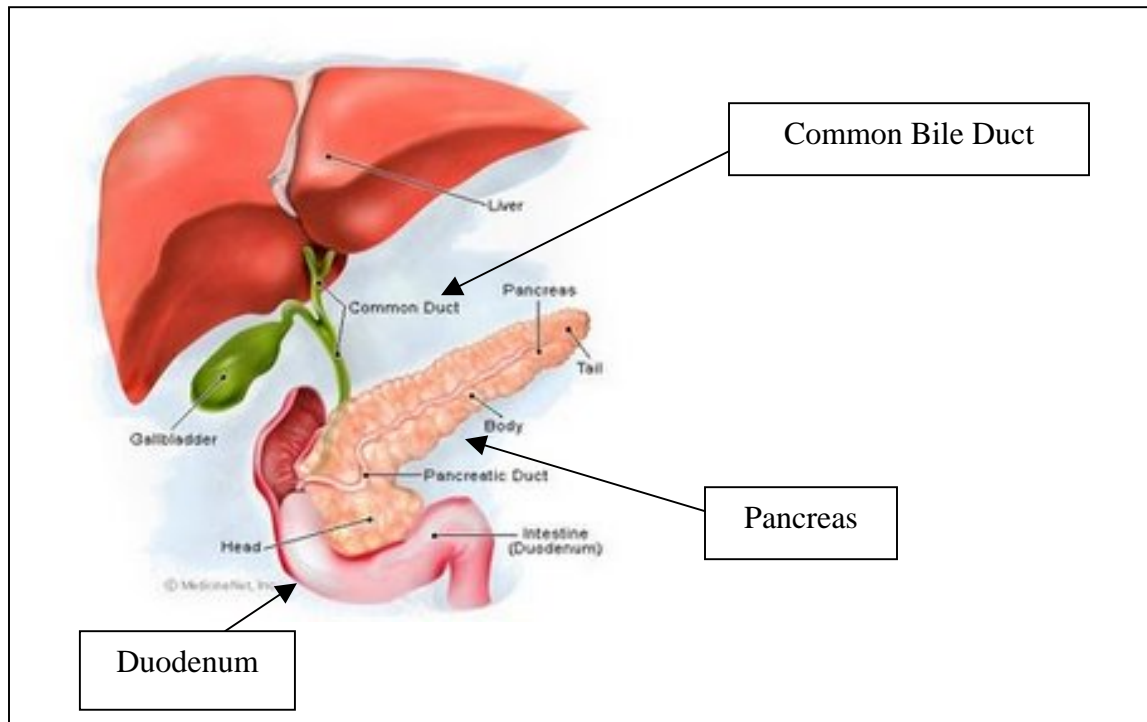
A silent disease

Pancreatic cancer can be called a silent disease because many times there are no signs or symptoms noticed until the cancer is in an advanced stage. Even when there are early signs and symptoms, they may be vague and easily attributed to another disease.

Jaundice

Jaundice is a yellowing of the skin and whites of the eyes. Signs and symptoms that may occur with jaundice are itching, dark urine, and clay coloured stool. The itching may be severe and cause a lot of discomfort especially at night when sleeping. Jaundice occurs when bilirubin stains the skin. Bilirubin is a dark-green substance made in the liver. The bile duct (see figure 3) connects the liver to the intestine and allows the

bile to flow from the liver into the intestine during the digestion. As the bile duct runs very close to the pancreas head, tumors in this area can block the bile duct creating a back-up effect of the bile that instead of going into the intestine accumulates in the blood causing jaundice.



GENERAL SYMPTOMS

Abdominal and Back Pain

A common sign of advanced pancreatic cancer occurs when the tumour presses on organs and nerves around the pancreas.

Fatigue and Weakness

People with pancreatic cancer may feel very tired.

Weight loss and loss of appetite

Very often patients affected by pancreatic cancer lose significant weight during the period that precedes the discovery of the tumour. This is caused by the fact that the cancer produces hormones that decrease appetite and other hormones that increase the energy requirement of the entire body.

OTHER ILLNESSES

Pancreatitis

An inflammation of the pancreas can be a sign of pancreatic cancer when it is chronic or when it appears for the first time and is not related to either drinking alcohol or gallstones.

Diabetes

Developing diabetes mellitus (sugar diabetes), especially after the age of 50, can be a sign of pancreatic cancer.

DIGESTIVE PROBLEMS OR PAIN

Nausea or vomiting

If the tumour blocks the upper part of the small intestine (the duodenum), nausea and vomiting may result.

DIAGNOSING PANCREATIC CANCER

Imaging tests

The most important tests used to detect pancreatic cancer are imaging tests such as ultrasound, CT scans and MRI scans. These tests use a variety of methods to see inside the body. Imaging tests can be simple x-rays or more complex scanning methods that use computers to reconstruct the structures in the body.

Computed Tomography (CT) scan

A CT scan, also called a CAT scan is a sensitive imaging test used to evaluate patients suspected of having pancreatic cancer and can produce three-dimensional images of the pancreas. It is estimated that this type of CT scan can diagnose about 98% of all pancreatic cancers and distant metastases.

Many people are familiar with or have had a computed tomography (CT) scan. During a CT scan, you will lie on a table that we move into the machine. The scanner will take detailed and cross-sectional x-ray images from many different angles. This test may take up to 2 hours and can be done on an outpatient basis.

Sometimes a dye, known as a contrast agent, can be injected into a vein but is usually given by mouth in order to produce better CT images of body structures such as the stomach and small intestines. In many centres, basic CT scanners are modified to see the pancreas more accurately.

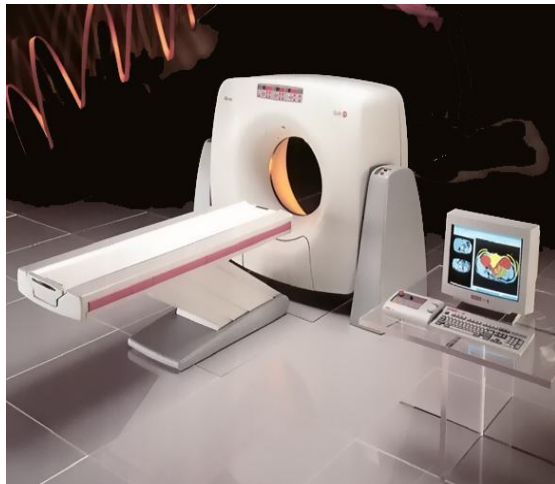


Figure 5: CT scan machine (above) and CT scan XR pictures (below)



CT scan is a painless procedure. Today's fast speed scanners can complete the imaging in less than 5-10 minutes, thus reducing the time needed to lay flat and still.

The only discomfort of CT scanning is the lying down flat for a few minutes. This may be of no consequence to most individuals but can be discomforting to those with neck and back problems. In addition, the CT scan does tend to cause a claustrophobic feeling because of the closed space enclosure.

When contrast is used, the individual may feel warm all over the body during the injection. This is a short lasting painless feeling. Others may complain of a metallic taste in the mouth. The rare individual may develop an allergy which may be associated with hives and itching.

There are many good reasons that people get CT scans. They are used by doctors to obtain additional information when initial symptoms or screening indicate that there could be a problem within the body. They are also used by individuals interested in taking preventive measures to avoid health problems by having their bodies checked out.

Magnetic Resonance Imaging (MRI)

Magnetic resonance imaging is another imaging method that is in common use today, and many people are familiar with it. This procedure is painless and does not require you to drink anything special or inject anything into your veins.

MRI uses radio waves and powerful magnets, instead of x-rays as in a CT scan, to view internal structures and organs. The waves are absorbed by the body and then released. A computer translates the patterns formed by this energy release into detailed images of areas inside the body. MRI produces cross-sectional slices like a CT scanner, but also produces slices that are parallel to the length of the body.



Magnetic Resonance Imaging (MRI) uses a strong magnetic field, radio waves, and a computer to generate detailed images of the body without the use of radiation. These images allow radiologists to diagnose many pathologic processes. MRI is widely used for imaging soft tissues in the body including the brain, nerves and muscles.



Magnetic Resonance Cholangiopancreatography (MRCP)

Magnetic resonance cholangiopancreatography (MRCP) is a type of MRI and is an alternative to ERCP. It is safer and faster than ERCP, because it is non-invasive and no dye is used. MRCP is used to view the pancreatic and bile ducts, which are difficult to see with CT or MRI.

Ultrasonography

Ultrasonography is another imaging test that is commonly used and many people are familiar with it. These scans are also referred to as ultrasounds, sonograms or ultrasonograms. During this test, sound waves are bounced off internal organs to produce echoes. The computer creates patterns from these echoes. Because echoes from normal and abnormal tissue produce different patterns, pancreatic cancer can be detected. This form of testing is non-invasive, painless, and can be performed in an outpatient setting.

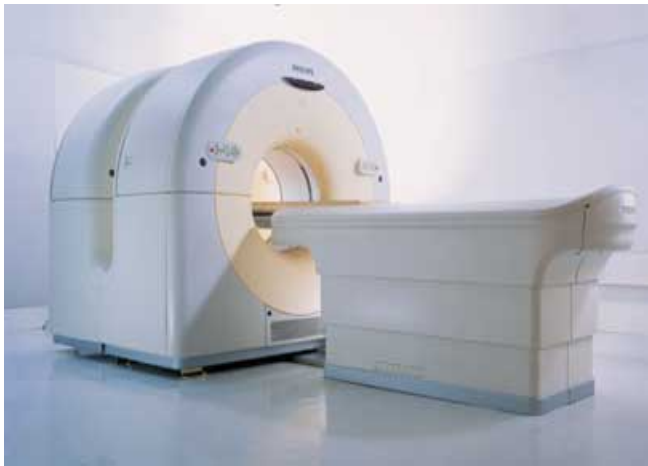
Figure 7: Ultrasound machine used to evaluate intra-abdominal organs



Ultrasound is a diagnostic exam that uses high frequency sound waves to produce real time images of the body. This is done by placing a transducer or wand-shape device against the area being examined. The high frequency sound waves produce echoes that are converted into electrical signals to create precise images of the body. Unlike x-ray, ultrasound does not use radiation; therefore it is considered a safe alternative for imaging pregnant women.

Positron Emission Tomography (PET scanner)

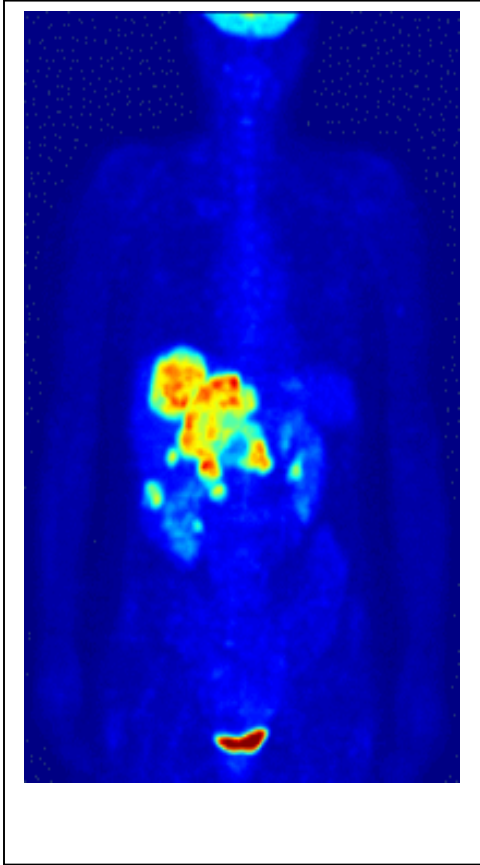
Positron emission tomography, or PET scan, is an imaging test that shows anatomy and biological function. During a PET scan, a small amount of radioactive glucose (sugar) is injected into a vein. Then a special camera detects the radioactivity that is taken up by cancer tissue.



PET scans are increasingly read alongside CT or [magnetic resonance imaging](#) (MRI) scans, the combination ("[co-registration](#)") giving both anatomic and metabolic information (i.e., what the structure is, and what it is doing biochemically). Because PET imaging is most useful in combination with anatomical imaging, such as CT, modern PET scanners are now available with integrated high-end multi-detector-row CT scanners.

Figure 8: Picture of the machine used to obtain PET scans

Below, copy of the picture obtained by PET scans machines.



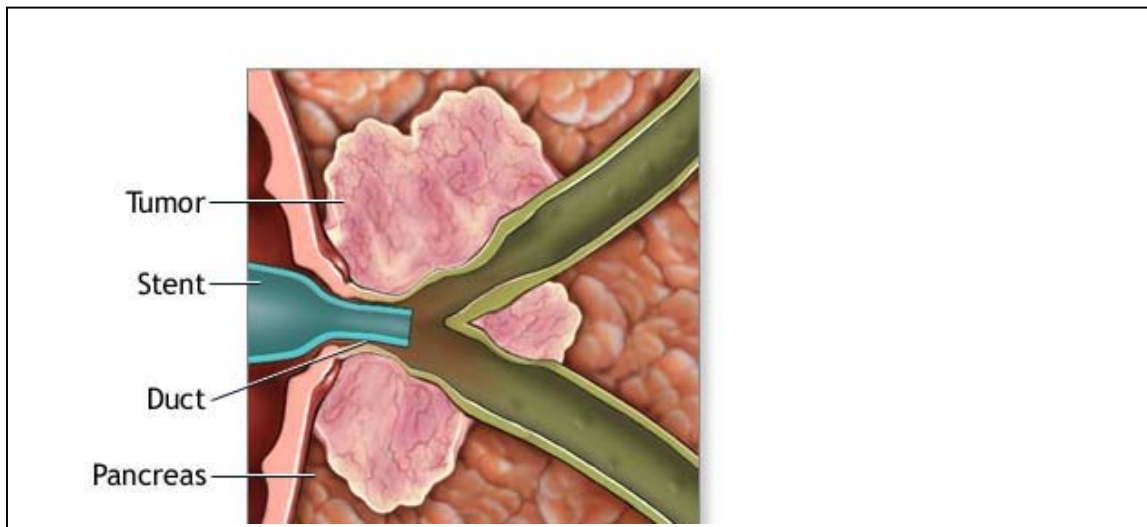
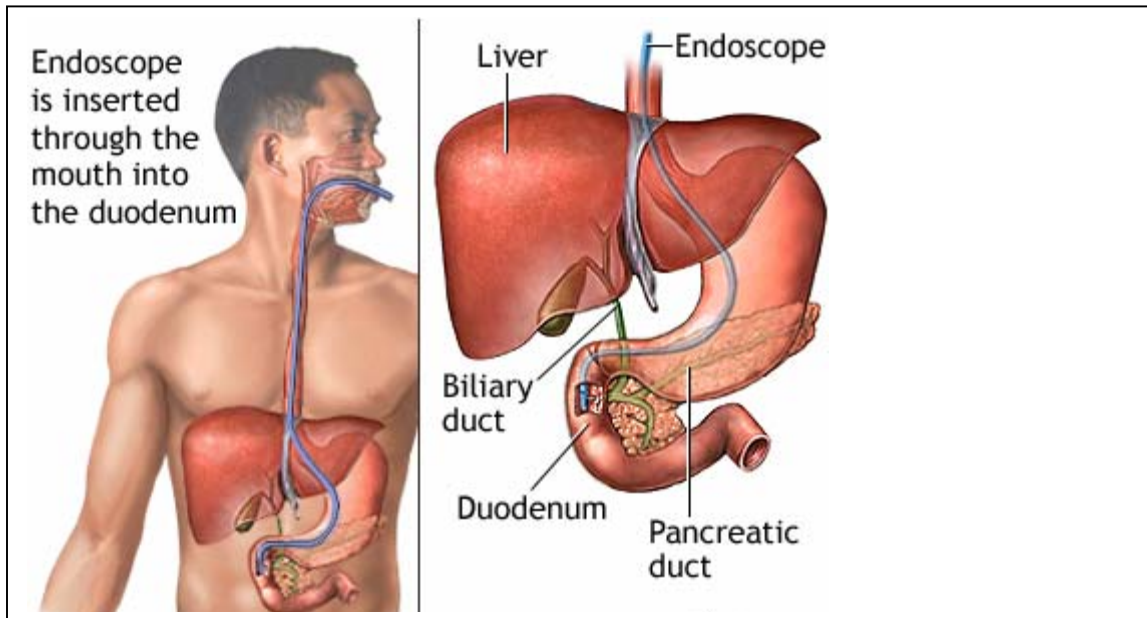
Because the two scans can be performed in immediate sequence during the same session, with the patient not changing position between the two types of scans, the two sets of images are more precisely [registered](#), so that areas of abnormality on the PET imaging can be more perfectly correlated with anatomy on the CT images.

Endoscopic Retrograde Cholangiopancreatography (ERCP)

Endoscopic retrograde cholangiopancreatography, or ERCP, is an invasive procedure that is used with a dye to view the bile and pancreatic ducts for any blockages. During an ERCP, you receive an anaesthetic to numb your throat and medication to make you sleepy. A thin tube is passed down your throat, through your stomach, and into your small intestine.

ERCP is especially helpful for patients with jaundice because a stent can be inserted and left in place to keep ducts open, often relieving the jaundice and its associated symptoms. In addition, during the ERCP doctors can collect small particles of any tumours there may be, to be analyzed under the microscope.

Figure 9: Graphical representation of an ERCP procedure and how the stent is positioned to keep the ducts open and prevent worsening of the jaundice.

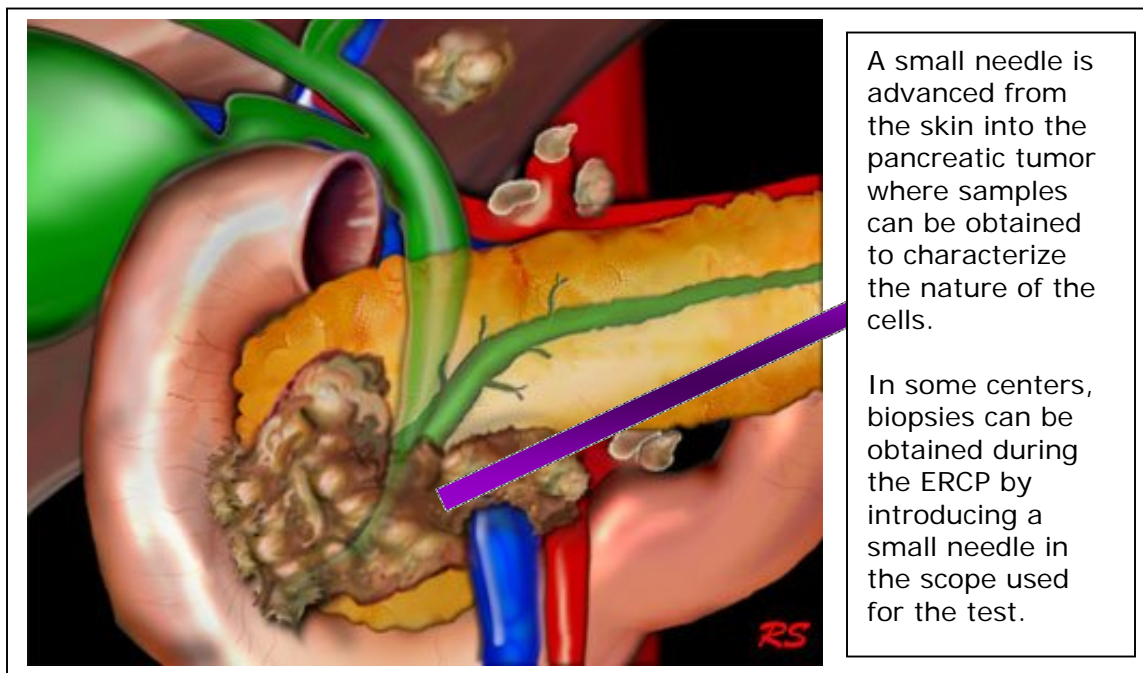


Biopsy

Because the only definitive way to diagnose cancer is to directly visualize cancer cells under a microscope, a biopsy may be performed when pancreatic cancer is suspected. A biopsy is the process of removing tissue samples, which are then examined under a microscope to check for cancer cells (Figure 10)

Fine-needle aspiration (FNA) is a technique in which cells are aspirated from a tumour using a needle and syringe with the application of negative pressure. The technique can be performed using image-directed guidance (Endoscopic Ultrasound-guided, CT guided) and is particularly helpful in the diagnosis of relatively inaccessible tumours. Cancer is then diagnosed if there is evidence of distinct, abnormal growth of cells.

Figure 10: Graphical representation of the pancreas and the tumour located at the head where the needle needs to be directed to obtain a sample of the tissue. The needle can be directed by using radiology instruments such as the ultrasound or CT scan.



There is some controversy regarding the use of biopsy tissue diagnosis of pancreatic cancer before performing surgery on a suspected tumour.

Some centres advocate the practice of operating on all patients thought to have early pancreatic cancer and argue against a preoperative biopsy tissue diagnosis. The concern is that false negative biopsy results can occur due a sampling error which could influence the decision to proceed with surgical removal of the tumor.

Some surgeons are hesitant to perform an operation on patients without a positive tissue diagnosis to confirm pancreatic cancer. Tissue diagnosis is almost always

required prior to initiation of chemotherapy, radiation therapy or the use of permanent metallic stents for relief in obstructive jaundice.

It is also possible that biopsy of the pancreas might spread cancer cells into the abdomen. Studies of the risk of spreading cancer with CT-guided biopsy have suggested that this risk is actually very low.

Blood tests

Unfortunately at this moment we don't have a single blood test that can be used to make a diagnosis of pancreatic cancer.

Different tumour markers in the blood are used to detect and monitor many types of cancer. Tumour markers are substances produced by some tumour cells. There are two commercially available tumour marker tests are of use in patients with pancreatic cancer: cancer antigen 19-9(CA19-9) and carcinoembryonic antigen (CEA). These markers are not accurate enough to be used to screen healthy people for or to make a diagnosis of pancreatic cancer. However, CA19-9 and CEA are frequently used to track the progress of treatment in patients with pancreatic cancer.

STAGING PANCREATIC CANCER

Staging cancer is a standardized way to classify a tumour based on its size, whether it has spread, and where it has spread. It measures the extent of the disease. Knowing the stage of your cancer will help your doctor determine which treatment options are right for you. Patients should know that the diagnosis and staging of cancer is a complicated process and that cancer is different in every person.

The diagnosis of pancreatic cancer is not complete unless staging (the stage to which the cancer has progressed) is done. Subsequent decisions about treatment will be based upon the stage assigned.

The results of various tests will determine the stage. Generally speaking, different stages carry different prognoses (see table below). The charts reproduced below are commonly used to stage pancreatic tumors.

Table: 5 year survival of patients diagnosed with pancreatic cancer by each stage at the time of diagnosis.

Stage at diagnosis	5-year Survival
Localized	10-16%
Regional	7-10%
Distant	2%
All stages	4%

Metastasis Evaluation (M)

Pancreatic cancer may spread locally to the lymph nodes and major blood vessels near the pancreas or to distant lymph nodes or organs such as the liver or lungs. In staging, this spread is documented as follows:

STAGING SYSTEM

Stage 0: refers to cancer that has not invaded outside the ducts in which it originated. This tumour can be removed by surgery.

Stage IA: The tumour in the pancreas is 2 cm or smaller and has not spread to lymph nodes or other parts of the body. This tumour can be removed by surgery.

Stage IB: The tumour in the pancreas is larger than 2 cm and has not spread to lymph nodes or other parts of the body. This tumour can be removed by surgery.

Stage IIA: The tumour extends beyond the pancreas but has not spread to nearby lymph nodes, major blood vessels, or other parts of the body. This tumour can sometimes be removed by surgery.

Stage IIB: The tumour is any size and is either limited to or extends beyond the pancreas with spread to the lymph nodes but not to the major blood vessels or other part of the body. This tumour can sometimes be removed by surgery.

Stage III: The tumour has spread to major blood vessels and possibly to the lymph nodes, but not to other parts of the body. This tumour can sometimes be removed by surgery.

Stage IV: The cancer has spread to other parts of the body.

CLINICAL CLASSIFICATION

Doctors often use a simpler, more descriptive staging system for pancreatic cancer. This system divides the cancers into groups based on whether or not the tumour can be removed surgically.

Resectable cancer: this is the type of pancreatic cancer that can be surgically removed. These tumours may lie within the pancreas or extend beyond it, but there is no involvement of the critical arteries or veins in the area.

Locally advanced cancer is confined to the area around the pancreas but cannot be surgically removed because the tumour may be intertwined with major blood vessels and may have invaded surrounding organs, but has not spread to other areas of the body.

Unresectable cancer: **a) Metastatic** cancer is when the tumour has spread beyond the area of the pancreas and involves other organs, such as the liver or lungs, or other areas of the abdomen. Unfortunately, almost half of all patients are diagnosed at this stage and **b) Advanced local cancer:** it is a tumour that has not metastasized yet but it has involved vital structures around the pancreas that cannot be safely removed by surgery.

MAKING DECISIONS ABOUT THERAPY

The ultimate goal of all the tests ordered by doctors is to recognize what kind of tumour patients are affected by and recommend possible treatments. Only patients can decide if they will accept that recommendation, and ultimately, where they will be treated and by whom.

Important questions to ask before beginning treatment for pancreatic cancer are:

- 1) Do I need any more information before I begin treatment?
- 2) Do I have confidence in the diagnosis?
- 3) Do I have confidence in my doctors?
- 4) Do I have confidence in the hospital?
- 5) Do I understand what will happen before, during, and after treatment?
- 6) How far from home am I willing to travel to be treated?
- 7) Do I want what is the current “standard of care” or am I interested in participating in clinical trials?
- 8) Do I know the possible complications that can occur during my treatment?
- 9) Do I know the possible benefits of the treatment?
- 10) Do I need a second opinion?

Facing Treatment Challenges

The best treatment results are obtained if surgery can be included as part of the treatment when pancreatic cancer is found at an early stage, before it has spread. Despite the great increase in research into pancreatic cancer, early detection is uncommon. It may feel much safer and simpler to take the advice of the doctor who diagnosed your cancer, but getting a second opinion by an expert in your type of cancer may be a wiser choice.

The National Cancer Institute recommends that all patients with cancer get a second opinion for two reasons: 1) to confirm the diagnosis and 2) to review the proposed course of treatment.

Multidisciplinary Clinics Dedicated to Pancreatic Cancer.

Today, more and more cancer centres are opening multidisciplinary clinics specifically dedicated to pancreatic cancer. The goal is to provide the highest quality of care. Patients who have suspected or known pancreatic cancer may receive a comprehensive evaluation that uses all of the resources available at these clinics for the diagnosis and treatment of pancreatic cancer. This includes highly trained doctors and specialists. The most advanced treatments are offered at these centres.

Oncology Treatment Teams

It is especially important to seek out specialists who have experience in treating pancreatic cancer. There are a number of healthcare professionals who have advanced knowledge and skills in oncology and specialize in treating patients and families affected by cancer.

Typically, there is one doctor who is in charge of your care along with an entire team of expert healthcare professionals who are involved in helping you to carry out your individualized treatment plan. This 'multidisciplinary' team approach ensures that you receive the maximum benefits of coordinated and comprehensive care that is designed to achieve the best possible healthcare outcomes.

Treatment teams for patients with pancreatic cancer may include a variety of doctors that include:

Surgeons

Medical oncologists: medical doctors who prescribe anticancer medications.

Radiation oncologists: specialize in treating cancer with radiation.

Endocrinologists: specialize in disorders of glands of the endocrine system.

Gastroenterologists: specialize in disorders of the digestive system.

Other team members may include: **oncology nurses, social workers, psychologists, dieticians, physiotherapists, pharmacists, and physician's assistants.** These individuals are professionally trained in a variety of specialized and advanced skills that include counselling, treating, and supporting patients and their families in navigating their cancer journey.

SURGICAL TREATMENT OF PANCREATIC CANCER

Surgery

Surgical removal of the tumour as part of the treatment is the only way to cure pancreatic cancer. Surgery is performed when the surgeon believes all of the cancer can be removed. This generally applies to patients who are in the early stages of pancreatic cancer.

Pancreatic surgery has improved significantly over the past two decades. Even so, surgery to remove a pancreatic tumour is both complex for the surgeon to perform and difficult for a patient to undergo. Recovery after surgery is usually relatively slow often taking several weeks. Complications from the surgery are not uncommon.

It is very important for patients before making a decision, to discuss with their doctors the risks and benefits of this type of surgery. Equally important is the need for patients to find both a surgeon and a facility that has a great deal of experience in performing this procedure. It cannot be emphasized enough that patients suffer far fewer surgical complications at centres that perform these surgeries often compared to centres that do fewer surgeries.

Procedures to Remove the Tumour

Three major procedures are used to remove pancreatic tumours:

- 1) Whipple procedure (pancreaticoduodenectomy)
- 2) Total pancreatectomy
- 3) Distal pancreatectomy.

Pancreaticoduodenectomy (Whipple procedure)

As the majority of cancers originate in the head of the pancreas, pancreaticoduodenectomy, is the most common surgery performed to treat pancreatic cancer. This technique is often called the *Whipple procedure* since it was named after American surgeon Dr. Allen Whipple who in 1935 devised the procedure. Since then, there have been multiple refinements to his technique.

During the operation, the surgeon removes the following organs:

- Most of the duodenum (the beginning of the small intestine)
- Head of the pancreas
- Part of the bile duct
- Gallbladder
- Lymph nodes in the area of the pancreas

After these organs are removed, the stomach, or the remaining part of the duodenum pancreas, and remaining part of the bile duct are joined to the small intestine. This

allows bile and pancreatic enzymes to enter the digestive system normally and mix with ingested food (Figure 11). On average, the Whipple procedure is performed in 6-8 hours. In some cases, if the patient has had previous abdominal operations with subsequent formation of scar tissue the surgical procedure can take longer and the risks of requiring blood transfusions or developing complications increase significantly.

Complications and Risk of Death

Pancreaticoduodenectomy is considered by any standard, a major surgical procedure with significant rates of complications. The risks of death after this operation are fewer in hospitals where this procedure is done often; however this procedure still carries a significant degree of risk. Most recent data show that the risk of death is currently in the range of 1.6-5%, with an average length of hospital stay between 8-14 days; possibility of admission to intensive care units exists for 12-15% of patients, blood transfusions may be necessary in 10% of cases, and re-operations may be required for 5-6% of patients.

Possible complications that patients may experience post-operatively include:

- Infections (incision, lungs, urine, in the abdominal cavity)
- Blood loss during surgery requiring transfusions (10% of cases)
- Leaking of bile or pancreatic juices (10% of cases)
- Difficulty emptying the stomach after eating (10-15% of cases)
- Inflammation of the pancreas (rare)
- Failure of other organs, such as the heart, kidneys and liver (rare)

Benefits of Surgery

Without surgery, the average survival of patients with pancreatic cancer is less than one year and very few survive more than 3 years. A successful Whipple operation can improve the chance of cure to 10-20% at 5 years after surgery. The operation aims to completely remove the cancerous growth, and gives patients the best chance of cure. That is why a wide area of tissue around the affected part is removed. The chance of the cancer recurring depends on the type of tumor. This will only be accurately known after the operation when the pathologist doctors examine the tumor under the microscope.

After the operation patients are admitted to the surgical unit where the nursing staff will monitor their progress and administer painkillers. Patients are placed on intravenous and usually not allowed to eat for the first 5-6 days.

Most patients are able to go home 7-14 days after surgery where they will most likely find movement and activity difficult for the first few weeks and require some help from family or friends. Their ability to eat can take several months to improve. In addition, patients may experience a low mood that usually resolves in a few weeks. Patients

often return to their normal activities after 2-3 months. There are usually no restrictions on activities after that time.

As the pancreas produces insulin that is required for control of blood sugar, there is a risk of developing diabetes following surgery. Patients who are not diabetic before surgery are unlikely to develop diabetes afterwards. Patients who are diabetic before surgery are likely to need additional diabetic medications or insulin after the operation.

Possible long-term consequences of the Whipple operation include malabsorption, weight loss, and a need to make dietary changes.

Malabsorption: Refers to the poor digestion and absorption of food, resulting in loose stools that are greasy, pale and tend to float in the water. The pancreas produces enzymes required for digestion of food. Removal of part of the pancreas decreases the production of these enzymes. Therefore, in some patients there is need for long-term treatment with pancreatic enzyme capsule supplements to be taken by mouth with each meal.

Weight loss: it is common for patients to lose weight compared to their weight before their illness. Usually by three months after surgery patients start regaining some of the lost weight.

Alteration in diet: after the operation, there is no restriction to patients' diet though most of the individuals after the Whipple procedure, where part of the stomach is usually removed, will only be able to eat small amounts of food at one time. Patients may need to have small meals with snacks between meals in order to minimize symptoms of bloating or discomfort. Dieticians can give advice about diet and supplements that can be taken to improve patients' nutrition. In general, it takes several months for digestion to improve and the ability for the patient to eat at a normal level.

Distal pancreatectomy: In this operation the body and tail of the pancreas are removed if the tumor is located in one of these two areas. The spleen is also removed at the same time as the blood and lymphatic vessels of the spleen are the same as the pancreas.

Total pancreatectomy: In this operation the entire pancreas, part of the small intestine, part of the stomach, the common bile duct, the gallbladder, the spleen, and nearby lymph nodes are removed.

Pancreaticoduodenectomy versus total pancreatectomy

Some doctors advocate the removal of the whole pancreas ([total pancreatectomy](#)) instead of just the head even for patients who have the tumor located in the head of their pancreas. However, studies have failed to demonstrate significant survival benefits, mostly because patients who submit to this operation tend to develop a particularly severe form of [diabetes](#) (so-called [brittle diabetes](#)).

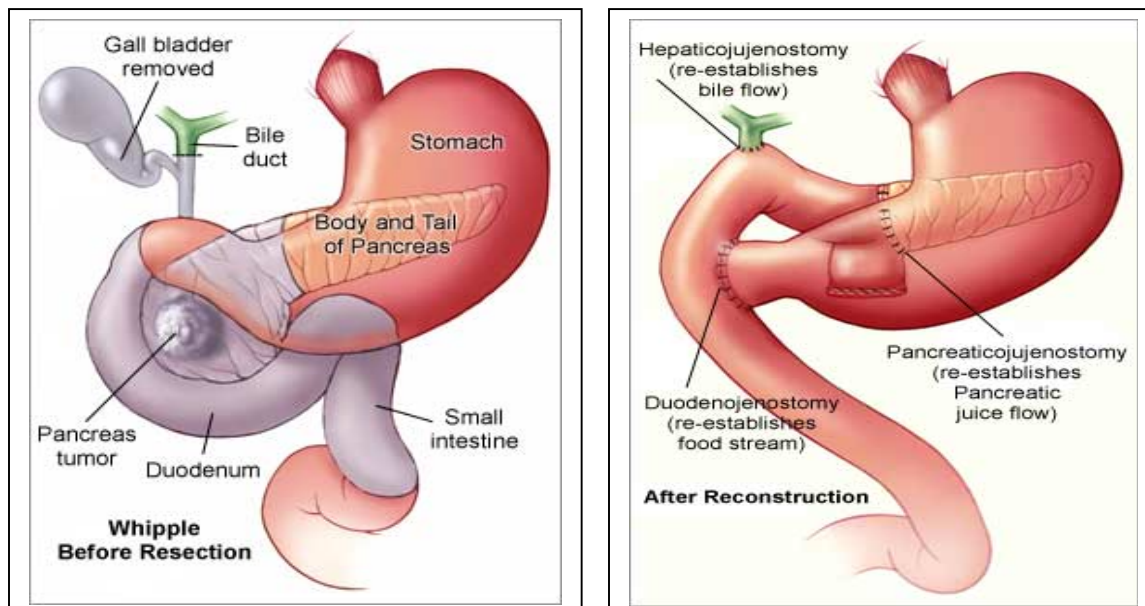


Figure 11: The Whipple procedure (pancreatoduodenectomy) is the most common operation performed for pancreatic cancer and may be used to treat other cancers such as small bowel cancer. Surgeons remove the head of the pancreas, most of the duodenum (a part of the small intestine), a portion of the bile duct and sometimes a portion of the stomach. After the pancreatoduodenectomy, the surgeon reconstructs the digestive tract

Prognosis of pancreatic cancer

Statistics are averages based on large numbers of patients. It is difficult to predict exactly what will happen (prognosis) to each patient following surgery since no two patients are exactly alike. Response to treatment will vary from one person to another.

Doctors use the term '5 year survival' to report the results of any treatment for cancer. This refers to the proportion of patients who are still alive 5 years after diagnosis. In any research study doctors follow what happens to people for 5 years after treatment because there is only a small chance that pancreatic cancer will come back 5 years after treatment. Doctors are reluctant to say that these people are cured because of that small chance. Thus the term '5 year survival' is used instead.

Outcomes

As with many other types of cancer, the outcome depends on how advanced the cancer is when it is diagnosed. In other words, it depends on the stage of the disease. Generally speaking, pancreatic cancer diagnosed early will have a better outlook than pancreatic cancer diagnosed when it is advanced.

Overall, pancreatic cancer has a poor prognosis. By the time someone has symptoms, goes to their doctor, and is diagnosed the disease is very often quite advanced. Only about 15 to 20 out of every 100 diagnosed patients (15 – 20%) are suitable for surgery.

Most people diagnosed with pancreatic cancer are told that they may have less than 1 year to live. However based on specialists' clinical trials being carried in leading cancer centers throughout the world, there are increasing reports of slightly better statistics. Much more research and clinical trials must be conducted before the outlook for people with this pancreatic cancer improves.

Of all those people diagnosed with pancreatic cancer, about 10 to 15 in every 100 people (10 to 15%) are alive 1 year later. Sadly, only about 3 out of every 100 people diagnosed (3%) live for at least 5 years after diagnosis. At 10 years after diagnosis the figures are almost the same as those at 5 years. About 2 in every 100 people (2 %) live for at least 10 years.

Early stages

Even for those people diagnosed in the early stages of this disease the outcome is quite poor. If the cancer has not spread outside of the pancreas and surgery is possible, then about 15 out of 100 people (15%) will be alive 5 years later. In those who do not live this long, it is likely that a small number of cancer cells have 'escaped' from the pancreas and traveled to other parts of the body. These cells are capable of growing into other tumors later.

Advanced stages

Sadly, for people diagnosed with advanced pancreatic cancer the 5 year survival rate is very low - about 1 in 100 people (1%).

Other factors affecting prognosis

There are 2 other factors that can affect your prognosis, apart from the stage of the cancer. These are:

- The grade
- How well the patients are overall (performance status)

Cells are graded according to how like or unlike normal cells they are when looked at under a microscope. There are 4 groups of cancer cells graded according to their size and appearance. Grade 1 cancer cells are the most similar to normal cells; grade 4 cells are most unlike normal cells. Generally speaking, the higher the grade, the more quickly the cancer is likely to grow.

Doctors also grade how well patients are progressing. They refer to this process as 'performance status.' A score of 0 means that the patients are completely able to look

after themselves; a score of 1 means that patients are able to do most things for themselves, but need some help. The scores continue to increase depending on how much help patients need. These scores are relevant to survival because overall, the fitter people are and the more independent they become, the better able they are to withstand their cancer and treatment.

Reliability of cancer statistics

No statistics can accurately predict what will happen to each patient. Each person's cancer experience and how the body responds to treatment is unique. Individuals can respond very differently to the same type of cancer diagnosis. The statistics to tell us about the different treatments people may have had and how that treatment may have affected their prognosis are to this point, not detailed enough. There are multiple individual factors that determine treatment options, prognosis, and outcomes.

Table 6:

Summary of the outcome of patients affected by pancreatic cancer by tumour stage at the time of presentation.

Tumor Stage	Description	Percentage of pancreatic cancer cases at the time of presentation	Treatment options	Median survival
Local / (resectable)	Disease is confined to the pancreas and is clearly separated from surrounding blood vessels	10%	Surgery; postoperative chemotherapy and/or radiation may also be offered	17 months
Locally advanced/ (unresectable)	Disease encases or compresses surrounding blood vessels, or has directly extended into adjacent structures	30%	Chemotherapy (most commonly gemcitabine-based) and/or radiation. In very rare instances, cancers that respond well to initial treatment may subsequently be surgically resected.	8-9 months
Metastatic	Evidence of extrapancreatic spread to distant organs (liver, lungs, etc.)	60%	Chemotherapy (most commonly gemcitabine-based); investigational trials	4-6 months

Palliative Surgery

Sometimes when cancer spreads and surgical removal of the tumour is not an option it may be necessary for patients to undergo what is known as a surgical bypass of the stomach or biliary duct in order to prevent persistent vomiting and jaundice caused by the tumour obstructing the stomach or the biliary duct. This is referred to as palliative surgery that is performed to promote the patient's level of comfort.

Radiation Therapy

Radiation therapy, also called radiotherapy, uses high-energy X-rays to shrink tumours by killing cancer cells. External beam radiation therapy is the type used most often to treat pancreatic cancer. A beam of radiation from outside of the body is focused on the tumour, similar to what is done during a diagnostic x-ray only at much higher doses of radiation. Some common side effects of radiotherapy are:

Common side effects of radiation therapy

- Skin changes (rashes, thinning)
- Nausea
- Vomiting
- Diarrhea
- Fatigue
- Loss of appetite
- Weight loss
- Worsening of chemotherapy side effects

Sometimes radiotherapy is combined with chemotherapy, called chemoradiation. This combination is often used when the cancer has spread and cannot be removed surgically.

Chemotherapy

Chemotherapy refers to the use of specific and highly toxic drugs designed to kill cancer cells. They can be recommended for patients before or after surgery or for individuals who are not able to be operated on as the tumor is already too advanced. Chemotherapy may be given by mouth or by injection, or may be delivered intravenously through a catheter positioned in one of the large veins.

The chemotherapy drug or drugs enter the bloodstream and travel throughout the body to reach the tumor cells. Chemotherapy may be used alone or in combination with either radiation therapy or surgery. Chemotherapy medications have been shown to decrease the chances of the tumor returning or continuing to grow.

In the past, the most common chemotherapy drug given to patients with pancreatic cancer was single-agent fluorouracil known as 5-FU. Other drugs (cisplatin, oxaliplatin, and taxanes) are used alone or in combination with 5-FU. The introduction of

gemcitabine (Gemzar) has changed the treatment of pancreatic cancer. Studies show that gemcitabine is better than 5-FU for treating metastatic cancer of the pancreas. Although chemotherapy is often used for patients with pancreatic cancer, the effects of chemotherapy are not very encouraging as this tumor has a tendency to be resistant to the treatment.

Targeted therapy is designed to kill only cancer cells and not normal healthy tissue. Targeted therapy is being used to treat pancreatic cancer. Erlotinib (Tarceva) targets a protein in the cancer cell that stimulates growth. Erlotinib is approved by the Food and Drug Administration (FDA) when used in combination with gemcitabine for the first-line treatment of patients with pancreatic cancer that is locally advanced, is inoperable, or has metastasized.

Side effects of chemotherapy

The side effects of chemotherapy depend on which drugs are used, the dose, and the length of treatment. Generally the chances of side effects occurring increase with higher doses and the use of a combination of chemotherapy drugs.

Chemotherapy may potentially affect healthy tissue. Most side effects disappear once treatment is stopped. Some of the more common side effects of chemotherapy are:

Usually not serious side effects

Fatigue
Hair loss
Loss of appetite
Mouth sores
Nausea
Vomiting

Potentially serious side effects

Bleeding or bruising
Low blood count
Infection

CLINICAL TRIALS

Clinical trials is a scientific term for the study of a drug, procedure, or medical device. Clinical trials are performed to determine if the product being tested is safe and effective for use in people. Doctors and other healthcare professionals run clinical trials according to a strict set of rules and guidelines established by the Food and Drug Administration (FDA) to ensure that study participants are treated safely and ethically. There are many different types of clinical trials which are used to find better ways to prevent, screen, diagnose and treat diseases, and to improve patient's quality of life.

Pain Management

World Health
Organization Analgesic
Ladder

Dr. Ian Beuprie, MD, FRCPC
May 2011

Craig's Cause Pancreatic Cancer
Society

PAIN MANAGEMENT IN PANCREATIC CANCER:

Identification, assessment and treatment of pancreatic cancer pain is vital to the pancreatic cancer patient who has pain. Successful treatment of pain in pancreatic cancer patients is achievable. Each person's response to pain is unique and dependent on different physical and psychological factors. It is important for the pancreatic cancer patient to discuss their treatment options for pain management with their health care team.

Types of Pain

Pain is classified as mild, moderate or severe.

- **Acute pain** can range from mild to severe and is pain that comes on quickly and lasts for a short time.
- **Chronic pain** can range from mild to severe and it either does not go away or comes back frequently.
- **Breakthrough pain** is an intense rise in pain that occurs suddenly and is usually felt for a short period of time. Breakthrough pain can occur several times a day and may occur when medication is wearing off.

What Causes Pain for People with Pancreatic Cancer?

Pancreatic cancer pain can be caused by the tumor obstructing flow (of bile or pancreas enzymes or the bowel contents) or else by invading nearby nerves or other structures. Some pain may be relieved by fixing the obstruction such as placing a stent.

Pain can also be caused by side effects from chemotherapy, radiation, surgery or other treatments.

Make sure you discuss your pain with your health care team to determine the origin and potential treatment options.

Pancreatic Cancer Pain Can Be Managed

The first step to the successful treatment of your pain is to talk honestly about it. You are the only one who knows what you are feeling and how it is affecting your life. It is important to be able to talk with your family and health care providers about what you are feeling.

Do not wait until the pain is unbearable before discussing options with your health care team. Pain is easier to control when it is mild. Stay ahead of your pain before it takes control of your life. Do not try to hold off between doses, follow the dose schedule given to you by your doctor.

Pain can be the primary concern of patients with advanced pancreatic cancer but it should be noted that not all pancreatic cancer patients will have pain. However, if you do experience pain it can be successfully managed. Often abdominal pain is the first symptom of pancreatic cancer. This mid-abdominal pain often radiates to the back area. When pain is not treated properly it can have significant negative effects on the patient and can lead to anxiety and depression. It is important for patients and families to know that there are options for the management of pain. The majority of patients can find excellent pain control with the help of their health care team. An integrated and knowledgeable approach toward pain will result in good pain control for almost all patients with advanced pancreatic cancer.

Describing Your Pain:

- Where do you feel the pain?
- When did it begin?
- What does it feel like? Sharp? Dull? Throbbing?
- Does it prevent you from doing your daily activities?
- What relieves your pain?
- Is your pain worse at different times of the day? If so when?
- Is your pain worse before or after eating?
- What have you tried for pain relief?
- Is your pain constant? How often does it occur and how long does it last?

Pain Control Options (This section written by Dr. Ian Beauprie)

Most pain associated with pancreatic cancer can be reduced with a simple formula called the 'World Health Organization analgesic ladder'. This is a set of steps, starting with simple pain medicines and progressing as needed to stronger Opioid pain killers:

- 1-Tylenol or Ibuprofen taken on schedule around the clock
- 2-weak pain killers such as Codeine or Tramadol as needed
- 3-stronger painkillers such as Morphine as needed
- 4-long acting strong painkillers taken every 12hours with short acting 'breakthrough' doses as needed.
- 5-pain relieving antidepressants (Nortriptyline etc) or nerve pain medicines (Gabapentin etc.) or steroids (Decadron, Prednisone).

Codeine is not a painkiller but is usually converted in the liver to morphine. Not everyone converts Codeine well so it won't work for everyone. Other painkillers (opioids) are similar to each other but vary in strength. Hydromorphone is five times

stronger than morphine, and methadone is variable but can be 10-17 times stronger. All opioids cause drowsiness that gets better with time and constipation that does not.

Coeliac plexus block is often used for belly pain from pancreas cancer. It is a needle placed in the midback to the nerves from the pancreas. It can be done by a pain specialist or a radiologist. Usually step one is to see if test freezing will help and a few days later to repeat the injection with something that kills the nerves (phenol or alcohol). This is called a permanent nerve block but really only lasts six months. It can be repeated if it wears off. The rare but serious risk of the procedure is accidental flow of the medicine into the spinal cord causing paralysis, but this is very rare.

When A New Pain Control Plan Might Be Needed

These are some things to watch for and discuss with your health care team:

- Your pain is not getting better or going away
- Your pain medicine does not work as fast as it is supposed to
- Your pain medication does not last as long as it should
- You require breakthrough medication
- You have side effects that are not going away
- Pain is interfering with eating, sleeping or working

If your pain is hard to control do not give up hope. Your pain can be managed.

Pain is different for everyone. It is important to be as open and honest as possible about what is happening and what works and does not work for you. You have the right to receive the best pain control treatment options available. Good pain control allows you to focus on your life and do the things you want to be able to do. Make sure that your health care team listens to you and take your concerns seriously. If you are in pain and your doctor has nothing more to offer, ask to see a pain specialist. If you have difficulty locating a pain specialist or getting help contact a cancer center, hospice or oncology department.

References:

www.hospicenet.org/html/what_is_pain-pr.html
www.cancer.gov/cancertopics/coping/paincontrol

Nutrition

What to eat after undergoing the Whipple Procedure

April 2011

What to Eat After Whipple Surgery

You may need to make some changes to your diet to help you feel more comfortable.

- Eat 5-6 small meals a day (small meals are easier to digest).
- Eat slowly and chew your food well
- Drink at least 6-8 cups (1500 -2000 ml) of fluid a day
- Have protein with each meal and snack (You need protein to heal and to prevent infection. Good sources are meat, poultry, fish, eggs, milk products and smooth peanut butter).
- Do not eat fried or greasy foods

To prevent gas and bloating:

- For the first 4 weeks after surgery, do not eat raw fruits (except bananas), raw vegetables, salads, nuts, seeds, popcorn, or the gassy foods listed here:
 - Broccoli, brussels sprouts
 - Cabbage, cauliflower
 - Corn, green peppers
 - Onions, turnips
 - Baked beans
 - Carbonated beverages

Good fruit and vegetables choices to eat:

- Bananas
- Canned and cooked fruits
- Fruit and vegetable juices
- Cooked carrots, squash, white and sweet potatoes (peeled)
- Well-cooked string beans

Do I need to take pancreatic enzymes?

After your Whipple, your body may make fewer pancreatic enzymes that help digest your food. This may lead to oily diarrhea, stools that float, pain in the abdomen, bloating, gas and weight loss. Talk with your doctor, as you may need to take pancreatic enzymes with your meals.

What if my stomach is slow to empty?

Your stomach may take longer to empty. You may feel bloated, have discomfort or fullness lasting for hours, and nausea with or without vomiting. This should improve within a few weeks of surgery. These diet tips may help you feel better if your stomach is slow to empty:

- Do not eat big meals. Have small meals more often.
- Chew foods well, especially meats.
- Sit up while you eat and for 1 hour after.
- Limit high fiber foods. Choose plain white bread, rolls and bagels instead of whole wheat or multigrain. Choose cereals that have no more than 2 grams of fiber per serving. Do not eat raw fruits and vegetables, nuts, seeds or popcorn.
- Do not eat high fat, greasy or fried foods

If you have tried all this and still do not feel better, you can try a liquid or pureed diet, as these digest quicker than solid foods. Try liquids high in calories such as milkshakes and nutrition drinks.

What if I am losing weight?

It is important that you eat enough to maintain your weight and to help you heal. If you are losing weight, try these **High Calorie, High Protein Snack ideas:**

- Granola bars
- Muffins, biscuits, scones, bagels with cream cheese, jam or peanut butter
- Scrambled, poached, hard cooked eggs
- Cheese and crackers
- Cold sliced meat or poultry. (Try it in a wrap or sandwich)
- Canned tuna or salmon with mayo in sandwiches or crackers.
- Pudding, yogurt or custards
- Ice cream, sherbet or frozen yogurt
- Smoothies, milkshakes, eggnogs, floats
- Whole milk, soymilk, chocolate milk, hot chocolate
- Boost®, Ensure®, Nestle Breakfast Anytime® or other nutrition drinks

Let your doctor know if you are still losing weight more than a month after surgery.

Notes:

Advocacy

How to ensure great
care and treatment!

Craig's Cause Pancreatic
Cancer Society
(www.craigsc ause.ca)

Read, Read and Read

As a patient or family member of someone who has cancer, we suggest that you learn everything you can about your disease, the treatments available (both experimental and standard) and the side effects of the treatments. Becoming educated about your disease ensures that you will be able to make informed decisions about your treatment options. It allows you to take an active role in your care and treatment.

Question, Question and Question

Come armed with questions about the disease, treatment and experience that the doctor and hospital has, in treating your specific illness. You have the right to ask any question that will affect your health and treatment of the disease. This means you have the right to ask what experience and success your doctor has had, with treating the particular cancer you have.

Do not go to appointments alone

Patients afflicted with such serious diseases are often advised to not attend meetings alone. It is difficult enough accepting that you have cancer..... understanding, comprehending and remembering all the information about the disease and treatment is even more difficult. Remembering and keeping straight all the information, without that second set of ears can become frustrating and overwhelming for the patient.

Keep a journal

There will be many things to remember, so it is suggested that you keep notes, so you that you can refer back to them when needed. Many doctors and nurses will be meeting with you regularly, so you need to ensure that they are all on the "same page." It is extremely important that you keep the facts straight, as human error can occur, even amongst the best health care workers. Keeping a journal on each meeting or discussion will assist you in keeping the facts straight and will assist in straightening out any oversights or misunderstandings.

Be an advocate for your loved one

Quite often our loved ones, who are fighting cancer, no longer feel like themselves. They feel overwhelmed, confused, anger, depressed etc., and may no longer be their best advocates. Family and friends are often encouraged to take on this active advocacy role, during the treatment of their loved one. Becoming involved in the decisions of all treatment will often ensure that your loved one is getting the best care available.

Speak Up

This is your body and your health that is at risk. Do not be scared to speak up and ask for something, even if you do not think it is possible. You have the right to ask for what you need and want in your health care. You may not get what you want, but you may find out where you could get what you need.

Second Opinion

Don't be afraid to seek a second opinion. Respectable Doctors expect that you will get a second opinion. Your family doctor can usually refer you for your second opinion. Make sure the care and treatment that you are getting is the best, for you. Know that you can go outside of your province to get this care or outside of the country, if you so chose.

Clinical Trials

Clinical Trials are treatment programs that are available to patients looking for alternative forms of treatment. These research programs are conducted with patients to evaluate new medical treatments, drugs or devices with the hopes of creating new and improved methods of treating different diseases. Ask your Doctor where you can look into this further.

Questions to ask your physicians

Be informed. Ask
questions!

Resources

*Canadian Cancer Society

*John Hopkins Pancreas Cancer
Web

*National Cancer Institute of
Canada

*Craig's Cause Pancreatic
Cancer Society

Questions to Ask Your Physicians

Understanding what questions to ask, will aid in your ability to learn more about your disease and it will assist you in making informed decisions about your treatment. It is our hope that these questions will assist you in this process.

Diagnostic Questions

1. What is the specific name of my diagnosis?
2. What is the specific name of my cancer/what type of tumour do I have?
3. Where specifically is my cancer?
4. Has my cancer spread (metastasized) to other organs or tissues?
5. How large are the cancerous legions? (Is the tumour 3 cm in diameter or smaller, which may indicate a longer median survival)
6. Where did the primary cancer originate?
7. What stage is my cancer in?
8. Is there lymph node involvement?
9. What are the characteristics of my cancer? Is this a cancer that moves quickly to other parts of the body or does it move slowly?
10. What further diagnostic tests will I need? Get the specific names of these tests.
11. How long will the diagnostic tests take, before a decision about surgery is made?
12. Can I go anywhere else to get the diagnostic tests done more quickly?
13. Do I need a biopsy to confirm this diagnosis? If so what are the risks?
14. Is this diagnosis 100% accurate?

Doctor/Hospitals

1. Get a second opinion. Where and how do I get a referral for a second opinion?
2. Where was this Doctor trained and who did they study under? Can you see their CV?
3. Have you treated patients with Pancreatic Cancer before?
4. How many Whipple Procedures have you done in total?
5. How many Whipple Procedures do you do a month?
6. How successful have you been in treating patients with pancreatic cancer?
7. Have you participated in clinical trials involving pancreatic cancer treatments? If so what were these clinical trials?
8. Would you consider yourself a doctor who responds aggressively to this particular type of cancer?
9. What is your success in treating pancreatic cancer patients with Chemotherapy and Radiation?
10. Is this a Doctor that you feel comfortable with?
11. Does this Doctor take an interest in your care and not look irritated with your questions? Does the Doctor appear invested in your care?
12. How many Whipple Procedures does the Hospital do in a year? (high volume hospitals are hospitals who perform more than 16 Whipple Procedures a year)

Treatment Questions

1. What are my treatment options? Ask for ALL treatment options (*not just the treatment options the physician thinks is best for you*) that are available for this specific cancer. Write down **all** options so that you can refer to them later.
2. What are the pros and cons of each treatment option? What are the side effects of each of these treatments?
3. What are the risks to the treatments suggested? This includes either surgery or drug treatment.
4. What is the treatment that you recommend based on my test results and why?
5. Are you aware of any other treatments available at another hospital or with another physician?
6. Who will be in charge of my care specifically?
7. Where can I find the CV on the Doctor who will be in charge of treating me?
8. Where can I go to find out more about clinical trials available to me?
9. Where can I find information on alternative forms of treatment?
10. What are the medical establishments that specialize in treating this specific cancer?
11. If I decide against treatment what can I expect to happen?
12. What side effects can I expect from this treatment?
13. Will the treatment be on an in-patient or outpatient basis?
14. What type of expenses can I expect for medications?
15. Will there be other health care professionals involved in my care such as nutritionists, physiotherapists etc.

Educational Resources

1. What organizations are available for me to contact that deal specifically with this type of cancer?
2. What literature would you recommend for me to read about my cancer and where can I find it?
3. What facilities are involved in the research of this particular cancer?

Life Expectations

1. What will my life look like while I go through treatment?
2. Will there be physical limitations?
3. Will there be lifestyle changes?
4. Will there be dietary changes?
5. Will I be able to work?

Resources Used to Create This List of Questions

- * Canadian Cancer Society
- * John Hopkins Pancreas Cancer Web

Pancreatic Cancer Video
Dr. Michele Molinari

* National Cancer Institute of Canada
*Craig's Cause Pancreatic Cancer Society

CONCLUSION

This booklet accompanied by the video is intended to provide comprehensive information to those who affected by pancreatic cancer. It is well known that the prospect of dealing with this disease is daunting for patients, families, and clinicians. Every effort has been made to present you with information that is current, clear and helpful in order to provide you with the tools you will need to understand the disease, the available treatment options, and outcomes that will support you as you manage this illness.

You are an equal partner with the knowledgeable, competent, and skillful healthcare providers that will accompany you in your cancer journey. All are dedicated to ensuring excellent and compassionate care. The more you know and a positive attitude that embraces hope will be powerful tools in your treatment and recovery process.

It is our hope that this booklet and video will provide you with the basic knowledge to prepare you to go forward.

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